



VBF Awareness Day Newsletter

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SPECIAL EDITION©

2005 VBF Second Annual Awareness Day

The Second Annual Vascular Birthmarks Foundation Awareness Day was held on May 15, 2005. Over 70 families registered to hold fundraisers and awareness campaigns to benefit VBF and children and adults with vascular birthmarks.

This newsletter is dedicated to all VBF Awareness Day participants, including children with birthmarks, parents, VBF Board members, family and friends. Our heartfelt thanks and gratitude to all!

Special Awareness Day Events (\$5,000+)

We Care Bear



President and Founder Linda Rozell-Shannon and her daughter Christine designed the VBF We Care Bear for this year's Day of Awareness. The bears were sold via the VBF website and through family, friends and the VBF community, raising over \$5,800 to date. The VBF We Care Bears

will continue to be sold on the website throughout the year to help VBF raise awareness and much needed funds. A mini information brochure is attached to the ear of the bear

VBF Celebrity Spring Cleaning Ebay Auction

May 9-19, VBF Vice President Greg Antonelle and wife Elyssa hosted an Ebay Auction, which included personal

and signed memorabilia from celebrities and sports stars. Clay Aiken, Tony Bennet, Courtney Cox, Arnold Palmer and Terry Bradshaw are just some of celebrities who donated items.

Wine Tasting Party

Tom Koch, former VBF Vice President, and wife Patricia, hosted a winetasting party. VBF President Linda Shannon attended the event and was a guest at their home in San Marino, California.

Texas Hold'em Poker, Dinner and Silent Auction

August 5, Natalie and Brian Bolinger organized a poker tournament in Corinth, Texas. Also, included were a buffet, dinner, raffle, and silent auction.

Boston Marathon

April 8, Danielle Vihaos ran the 26.2 mile Boston Marathon in honor of her son and all children with vascular birthmarks.

Courage, Confidence Inspires Awareness



Fifteen-year-old Saige Cavayero was born with extensive facial hemangiomas of the lower lip, sides of face, and left neck region. VBF Founder, Linda Shannon helped the family find a doctor to treat her.

Saige shows her VBF bracelet

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COURAGE| From Page 1

“Because my family and I are so grateful to the VBF for their guidance,” Saige said, “I wanted to give something back to VBF by doing a mini-fundraiser.”

With the help of her mother Elysa Baron, a VBF Parent Rep., she designed and purchased 1,000 turquoise-colored silicone bracelets. The bracelets were debossed with the message “Courage Confidence VBF”.

Saige also distributed flyers to the students and staff at her local highschool, and organized a letter writing campaign to involve friends and family in the projet. In addition, Saige also helps to moderate the VBF Teen Discussion Board on the VBF website.

VBF Awareness Events hosted by members around the world

Brazil Events



Participants at the Brazil meeting.

Andrea Domingues of Sao Paulo, Brazil organized a meeting for parents, patients and doctors at a local hospital. Andrea had just discovered VBF, and had 15 days to

prepare for this event. Her efforts to organize and pull this meeting together were exceptional. In addition to lectures provided by doctors, Andrea spoke about her experiences as the mother of a child with hemangioma and lymphangioma. “Now we have started a movement,” she said. Andrea also organized a Yahoo community support group a year ago.

Canada Events

Rhonda Spuzak of Fort Frances, Ontario helped raise awareness for vascular birthmarks by writing two articles for local Canadian newspapers. Rhonda’s daughter Kenna has a hemangioma near the soft-spot area at the top of her head.

California Events

Tom and Patricia Koch of San Marino, CA hosted a wine-tasting event in their home, raising over \$6,300. Their son, Keenan had a beard distribution hemangioma. Tom is a former VBF Vice President.

Connecticut Events

Suzanne Walsh of Simsbury, Connecticut, raised awareness by hosting a skating event, raising \$550 for VBF. “Our major awareness success was having the Governor of Connecticut, Jodi Rell, proclaim May 15th Vascular Birthmark Awareness Day,” she said. Suzanne’s

daughter, Molly, had a nasal-tip hemangioma



Suzanne Walsh

Florida Events

Leigh Ann Gomillion and daughter Gabriella, of Land O Lakes, FL. sold toys and clothes to raise money for VBF. They collected \$37 for their efforts. Gabriella donated her own toys for this event. She had facial and internal hemangiomas.



Heather and Laura

Shelley Toulson, along with daughters Laura and Heather, hosted a lemonade stand in their

hometown of Weston, FL. The sisters sold \$31 worth of lemonade. Heather has a port wine stain on her right cheek.

Illinois Events

Amy Ledbetter, Charleston, IL, raised awareness by sending out an informational letter about her daughter Danae, and by holding a bake sale, as well as selling VBF We Care Bears. The family was also featured in

-See ILLINOIS EVENTS, page 3-

a story by their local newspaper. Their events raised \$620 for VBF Awareness Day. Danae has a venous malformation.



Danae Ledbetter

Indiana Events

Stephanie Shulz, of Avon, IN, collected \$100 from family members for VBF. Her daughter Meghan was featured in a local newspaper article, highlighting awareness and telling about her surgeries to remove a hemangioma from her lip.

Kentucky Events

Tiffany and Glen Ethington, of Lexington, KY, hosted "Glen's Birthday Celebration for VBF Awareness Day". Instead of birthday gifts, Glen requested that party guests donate to the VBF. He also sold We Care Bears and silicone bracelets, raising \$170. Tiffany is the VBF Secretary, cofounder of the Sturge-Weber Syndrome Community, as well as the VBF Kids Who Care Campaign Coordinator. Glen is the first participant for



Glen Ethington

the new event and has Sturge-Weber and a facial port wine stain.

Massachusetts Events

Danielle Vlhou, Boston MA, ran the 26.2 mile Boston Marathon on April 18, 2005, to raise funds and awareness for VBF. Inspired by her son Cole, who was born with a large hemangioma on his right ear, she raised \$5,000, but says her family's motivation doesn't stop there. They hope to form a team of 15 runners for the 2006 Boston Marathon. "To all the children that battle illness each day, you are our true inspiration," said Danielle. "Your bravery and courage is immeasurable."

Michigan Events

Christine Archer, Howell, MI, raised over \$1,000 for VBF. Her son Danny has a port wine stain birthmark, and was featured in a local newspaper article. Christine participated in the VBF Celebrity Spring Cleaning Auction on E-Bay.

In honor of her son Jonny, Holly Gregory of Three Rivers, MI, held Longerberger Basket raffle, raising \$1,690. Holly and family were also featured in two newspaper articles. Holly's son had two hemangiomas, and she says, "...It's great to connect with someone who knows how you feel".

Minnesota Events

Maria Larson, Mankato MN, sold VBF We Care Bears and asked friends and family for donations, raising \$240. Maria's daughter Elisabeth had a hemangioma on the bridge of her nose. Upon contacting VBF President, Linda Shannon, Elisabeth had surgery to



Elisabeth Larson

remove the lesion. "We will always be forever grateful and thankful to the VBF," Maria said.

Missouri Events

Elissa Rifkin of Clayton, Missouri, and her daughter Jacqueline ("Jaci") sold VBF silicone bracelets. Jaci had a facial hemangioma, and Elissa serves on the VBF Board and volunteers for the VBF "Ask the Developmental Specialist". She also volunteers at the Birthmark Clinic at St. Louis Children's Hospital.

Kelly Barkmeier, of Lee's Summit, MO, hosted a 1-mile walk, flower sale, sold VBF stickers, and mailed out informational letters, telling stories of children with vascular birthmarks. Kelly's daughter Lily has a hemangioma near her eye.

-See MISSOURI EVENTS, page 4-

The family and their event were also featured in a local newspaper article. Jeannie Johnson assisted the Barkmeier's with the events. Jeannie's daughter Ashly has a port wine stain on her leg. The events raised over \$2,100.



Left to right – Kelly Barkmeier, daughter Lily, Jeannie Johnson, and daughter Ashly.

New Jersey Events

Greg and Elyssa Antonelle, of Long Valley, NJ, hosted the VBF Celebrity Spring Cleaning Auction on E-Bay. Their efforts were written up in several local papers, and featured on radio broadcasts in New York and Atlantic City. Donations from Celebrities and Sports Stars numbered well over 100 items. Greg and Elyssa's son, Nicholas, has a lymphatic malformation. The event raised close to \$13,000. Greg also serves as VBF Vice President.

VBF Executive Director, Paige Salvador, of Mt. Laurel, NJ, hosted "Golf with the Girls". Paige and her girlfriends raised \$200 doing what they love – golfing! They look forward to doing this again next year.

New York Events

VBF Founder and President Linda Rozell-Shannon, of Niskayuna, NY, and daughter Christine, designed and sold collectible VBF We Care Bears. Christine, who was the inspiration for the formation of the VBF, gave the bears their name. Linda also hosted an awareness event at a local McDonald's restaurant on May 17. VBF board members, family and friends helped.

Lianne Chase of Albany, New York, called on friends, family and co-workers to help her celebrate Awareness Day. For her birthday on May 15, Lianne threw a party for VBF, raising over \$500. Vascular birthmarks affect both Lianne's sons, Casey and Cody. The family was featured in their hometown newspaper.



Cody & Casey at the "Scar Wars" Birthday party.

Saige Cavayero of Saratoga Springs, NY, along with her parents Elysa Baron and Keith Cavayero, raised over \$4,800 through the sales of "VBF Courage Confidence" silicone bracelets. Saige designed the bracelets, and also distributed flyers to students and staff at

her school to raise awareness. Saige was born with extensive facial hemangiomas. She was also featured in a local newspaper article.

Ohio Events

Teresa Crompton, held a garage sale in her hometown of Cleveland, OH on May 27-28, in honor of her daughter Isabella, who had a hemangioma removed only weeks before the event. Raising \$400, friends and family members Millie Simon, Fred Simon, Emily Rito, and Liz Sullo, and neighbors, helped with the event. "We are thankful for the help we received from the VBF," Teresa said.

In her hometown of Kirtland, OH, Sarah McCollum mailed out letter and VBF pamphlets to friends and family in honor of her son Devan. Big sister Shyanne also participated by sending letters and brochures home with classmates. The

students donated money, and Shyanne and Sarah constructed a poster about birthmarks and syndromes to share with her class. Along with donations from the local Kiwanis Club, they raised \$225.



Pennsylvania Events

Traci Lebofsky, Philadelphia, PA, raised \$1,000 by hosting “Breakfast and Bowling for Vascular Birthmarks”. The participants included family and friends. Traci’s daughter, Gioia, has a hemangioma.



The Lebofsky family and friends.

South Carolina Events

Jackie Burke and her daughter Abigail of Columbia, SC, celebrated VBF Awareness Day with the children who attend the Lakeside Outreach church in Santee, SC. The children “...all know about VBF because of Abbi,” said Jackie. With the help of her friends, Abigail raised \$800 for VBF. The child at Lakeside Outreach, who helped to raise the most money, received a large stuffed purple gorilla. Abigail has a venous malformation on her lip.



Abigail Burke (far right) and friends.

South Dakota Events

Robin Houwman of Sioux Falls, SD organized a pendant fundraiser to benefit vascular birthmarks. Robin is a member of the Vascular Birthmark Support Group on MSN Groups. The sale of pendants and zipper pulls has raised over \$3,000 for VBF.

Tennessee Events

Anne Marie Brooks, Carthage, TN, wrote an article for her local newspaper, highlighting an awareness event.

Texas Events

Brian and Natalie Bolinger of Corinth, Texas, organized a No Limit Texas Hold'em Poker Tournament in honor of “The Second Annual Nicole Bolinger Fundraiser Benefiting the VBF”. The event included dinner and a silent auction, raising over \$8,000. The Bolinger’s daughter, Nicole, has a facial compound hemangioma.

Vermont Events

Betsy Kenyon of Enosburg Falls, VT, raised awareness for vascular birthmarks by passing out informational pamphlets in her area. Her children’s daycare donated \$25 for VBF.

Wisconsin Events

Jennifer and Pete Kalmon of Wisconsin Rapids, Wisconsin, raised around \$150 by selling VBF Awareness Day stickers and holding a drawing for toys and rounds of golf. Their son Braeden had surgery to remove a hemangioma under his nose. The family was also featured in their local newspaper.

Karen Tooley, of Menomonee Falls, WI, emailed friends and family members, asking for donations. She raised \$535 for VBF Awareness Day.

Sandra and Todd Peters, of Appleton, WI, held a garage and baked goods sale in honor of their daughter Elizabeth, who had a hemangioma on her neck. The family also sold VBF stickers, building “Elizabeth’s Wall of Fame”, where the stickers would be placed on the wall with the name of the family donating. Elizabeth and family raised \$2,842 for VBF.



Elizabeth and “Wall of Fame”.



VBF Kids Who Care Corner

The Vascular Birthmarks Foundation is proud to announce the establishment of VBF KIDS WHO CARE©, a program created by VBF Founder and President Linda Rozell-Shannon that is geared toward school-aged children K-12. To head this program in a positive direction, the VBF is launching the VBF Kids Who Care - Birthmark Awareness Campaign. This campaign will help teach children "the spirit of community service, and the rewards of charitable giving, while raising awareness and the much-needed funds." This program is perfect for schools that promote courage and confidence and that teach children to respect and support other children who are different in any way

Spearheaded by Tiffany Ethington, VBF Secretary, and our first Kids Who Care Program Coordinator, the Birthmark Awareness Campaign will begin September 1, 2005 and culminate on VBF Awareness Day, May 15, 2006. You can join the program at any time during the school year. The minimum goal for each school participating is \$100. VBF has established a goal of 25 schools throughout the world to participate in our first VBF Kids Who Care campaign.

Schools and/or individuals can host a Birthmark Awareness Campaign by selling We Care Bears, Kids Who Care silicone bracelets, collect pennies through our Kids Who Care/Pennies for a Purpose drive, or host a DIY (do-it-yourself) campaign – like a bake sale, car wash, yard sale or lemonade stand.

VBF invites your child and local school to join us in this groundbreaking endeavor, because kids with vascular birthmarks do care. And we know that their siblings, friends and schoolmates care too. To participate in this very exciting program, download the introduction letter and the registration form and complete them with your school and mail them to our program Coordinator.

The concept for the VBF Kids Who Care program was inspired by several of VBF's own kids: Glen Ethington for his kids program at his school, Saige Cavayero for her silicone bracelet campaign and Christine Shannon for naming the VBF We Care Bear. In addition a public school in NYC raised over \$400 for VBF in a pennies campaign. All of these jointly inspired the creation of VBF Kids Who Care because all of these kids do care.

For more information, contact the KWC Program Coordinator, Tiffany Ethington at tethi@insightbb.com, P.O. Box 24890, Lexington, KY 40524-4890, (859) 272-3857; or visit the VBF website: www.birthmark.org.

Kids Who Care Help Raise Awareness for VBF

The following VBF Kids participated in The 2005 Second Annual VBF Awareness Day. The VBF salutes their hard work and dedication in helping support other kids with birthmarks.

- ❖ **Abigail Burke** and her friends at church collected money for VBF. Abigail has a venous malformation on her lip.
- ❖ **Saige Cavayero** designed and sold silicone bracelets engraved with VBF Courage Confidence. Saige was born with extensive facial hemangiomas.
- ❖ **Glen Ethington** hosted a birthday celebration for VBF, asking for donations instead of presents. Glen has Sturge-Weber syndrome and facial port wine stain.
- ❖ **Gabriella Gomillion** sold some of her toys and clothes for VBF. Gabriella had facial and internal hemangiomas.
- ❖ **Shyanne McCollum** made a poster about vascular birthmarks to educate her classmates. Her fellow students also donated money to VBF Awareness Day. Her little brother Devan, has a nasal-tip hemangioma.
- ❖ **Elizabeth Peters** sold VBF stickers, making a "Wall of Fame". Elizabeth had a hemangioma on her neck.
- ❖ **Jaci Rifkin** sold VBF silicone bracelets to support Saige and VBF. Jaci had a hemangioma on her nose.
- ❖ **Christine Shannon** named the VBF We Care Bear, and helped sell them with her mother, VBF President Linda Shannon. Christine had a hemangioma on her lower lip.
- ❖ **Heather and Lauren Toulson** sold lemonade for VBF. Heather has a port wine stain on her right cheek.

The 2006 Third Annual Vascular Birthmarks Foundation Awareness Day

What's missing in this newsletter? You! The VBF would like to highlight your story in next year's Awareness Day Special Edition Newsletter. Please don't forget to sign and return the **Registration/Questionnaire Permission to Publish Form** for next year's Awareness campaign.

Don't miss out on this opportunity to have fun while raising funds and awareness, and helping to educate the public about vascular birthmarks. Each and every event is important. Fundraisers can be simple, but effective. Friends and families joined in the 2004 and 2005 campaigns by holding E-Bay auctions, poker tournaments, car washes, birthday celebrations, and garage sales.

In 2005-2006, VBF introduces the **VBF Kids Who Care Birthmark Awareness Campaign**. This campaign will teach children in grades K-12 the rewards of community service and charitable giving. Registration for this event is already underway for the 2005-2006 school year, and culminates on VBF Awareness Day May 15, 2006. Get you school registered today!

Plans are underway for *The 2006 Third Annual Vascular Birthmarks Foundation International Awareness Day*, and the VBF is ready to help you make your event a success. Let our Awareness Day Committee assist you in organizing and planning your 2006 event.

To receive your VBF Awareness Day Registration Packet, or if you require more information, fill in and return the form below; or write to Paige Salvador at: VBF, P.O. Box 106, Latham, New York, 12110. Please include your name, address, telephone number, and email address.

2006 VBF Awareness Day Registration Packet Request

Please send me a VBF Awareness Day Registration Packet.

NAME: _____

ADDRESS: _____

CITY: _____

STATE: _____ **ZIP CODE:** _____

TELEPHONE: () _____

EMAIL: _____

I will be participating in the VBF Kids Who Care Birthmark Awareness Campaign: ____yes ____no

THE VBF IS WORKING FOR YOU

The VBF has networked over 20,000 patients into treatment since 1995

Helped to establish nine VB clinics

Website and Discussion Group

Annual Newsletters/Day of Awareness Newsletter

Doctor list and referral information

Ask the Experts/Ask-A-Nurse on website

2005 PWS Conference - Irvine, California

Family support and education/Physician education

VBF Branches – Israel/South America/Europe

Sturge-Weber Syndrome Community/SWSC Canada

VBF Programs – VBF Awareness Day/Babies with Birthmarks/Orphans with Birthmarks/Kids Who Care

Mission Statement

The Vascular Birthmarks Foundation is an international charitable organization that provides support and informational resources for individuals affected by hemangiomas, port wine stains, and other vascular birthmarks and tumors, while sponsoring relevant research and promoting physician education.



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